

The Federal Centre for AIDS: Working against a plague mentality

Lynne Cohen

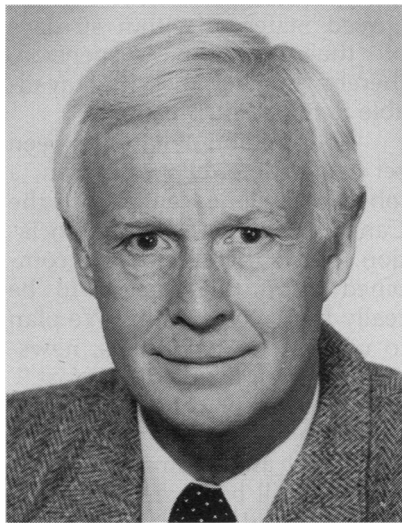
We've never seen anything that has had so much impact", Greg Smith says of AIDS. "And not just in terms of health."

As executive director of the Federal Centre for AIDS (FCA), he should know. The Ottawa-based centre — the Department of National Health and Welfare's first one-disease directorate — has the same status within the federal bureaucracy as the Laboratory Centre for Disease Control (LCDC).

Smith, who helped establish the centre, says AIDS is more than a disease. "Of course, AIDS has to be handled like a disease. But it has social, legal and ethical sides as well. It presents enormous educational challenges and business concerns and it has renewed discussions about how we approach sex in our society."

Such considerations are incorporated into the federal government's National AIDS Program, a 5-year, eight-point, \$39-million project announced in May 1986 by Health Minister Jake Epp. Although considered underfunded by FCA managers, the centre's director-general, Dr. Alastair Clayton, says the program still serves to advance the government's aim, "which is, in a broad statement, to provide the minister with strategies to control and manage AIDS in Canada".

The program's functions are to provide research support within and outside the government;



Clayton: some don't believe experts

to educate the public and health care professionals; to provide advisory committees at the national and interprovincial levels; to provide financial and informational support for community-based, nongovernmental AIDS groups; to fund and enhance diagnostic centres throughout Canada; and to organize and host the Fifth International Conference on AIDS, which will be held in Montreal in 1989.

Ottawa's response to AIDS changed as the public's concern did. "When AIDS was first 'invented' in 1981", says Clayton, "we immediately got cases at LCDC in Ottawa, where I was director-general for 9 years."

About 2 years after that first case was reported, then federal Health Minister Monique Bégin set aside \$1.5 million for research and public education and established the National Advisory Council on AIDS (NACAIDS). "As the problem burgeoned, we

created the National AIDS Centre, which Greg ran", says Clayton. "The thing just got bigger and bigger, so a year ago last May the government announced the national AIDS program and pledged the \$39 million." In the fall of 1987 the centre became the FCA directorate, with an expanded mandate, three times the staff and its own laboratories.

But that didn't mean NAC-AIDS disappeared. Dr. Norbert Gilmore, the council's chairman since its inception, says its membership and focus have changed, "but the mandate has stayed the same: to advise the minister on all aspects of the problem of AIDS in Canada".

Members, who volunteer their time, include doctors, nurses, lawyers, a psychologist, an epidemiologist, a virologist, a biologist, an immunologist and a public health worker. "We have been very important for the government", Gilmore told *CMAJ*. "We bring ideas from outside and provide a forum for officials to bounce ideas [around]."

At first, he says, the dozen or so experts belonging to NAC-AIDS dealt with detailed questions of science, care needs, prevention and the potential spread of AIDS. "We spent a lot of time on technical stuff like tests and treatments. We wrote a lot of guidelines and also ended up advising more than just the government. Now, with more and more expertise inside [the bureaucracy], we are focusing on things like the ethics of testing, educational approaches and research needs. And the issues keep changing. Right now we're dis-

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cusssing the screening of immigrants."

The FCA, which administers the National AIDS Program and provides the secretariat for NACAIDS, has 21 staff members — doctors, epidemiologists, laboratory scientists, technicians and communications specialists.

Its responsibilities are many and growing, says Smith. One of the biggest involves handling calls and letters from health groups and the public. "We answer more than 25 000 calls and 5000 letters a year — I get between 20 and 30 calls a day."

He says people phone with opinions "covering the whole waterfront, from 'AIDS is God's punishment for the deserving' to praise and encouragement for the health minister. And I get every kind of question imaginable, including some very interesting and graphically detailed descriptions of sex lives from people wanting to see if they are at risk".

The FCA gets requests for information from hospitals, schools, day-care centres and numerous other groups seeking educational material and guidelines. They often get what they need. "One of our main roles is to prepare guidelines", says Clayton. So far, the FCA has written more than 10 sets, including ones for pathologists, dentists, nurses, child-care attendants and, most recently, for workers in hospitals and clinics.

Research is a major part of the federal program. More than half of the entire budget — \$23 million — is being distributed to researchers across the country. The work resulting from this cash outlay augments the government's own research activities, which include attempting to develop vaccines and providing Canada's reference laboratory for testing for the human immunodeficiency virus (HIV). The government is also conducting surveillance studies to discover the prevalence of HIV in the country and is supporting clinical trials involving azidothymidine. Ottawa helped launch the trials in Canada in 1986 by giving the

drug manufacturer, Burroughs Wellcome, \$1 million. In an unprecedented move, the government also brought the company, government officials and persons with AIDS together to conduct the tests. "It is difficult at times", says Smith, "since the three groups often have different objectives."

But the move paid off. The government was able to move quickly to stop the use of placebos in trials — at the time they were considered unethical in the United States — within 40 days of the American suspension, thereby making the drug available to more AIDS patients.

Four million dollars has been set aside for public education, a job once assigned entirely to the Canadian Public Health Association. Now, there can be a combined effort. "It's going to be really big", says Smith. "We plan to use videos, pamphlets, newspaper ads; all the media, in fact."

He says the campaign is embryonic, since the educational materials and communications plan are still being devised: "We want to find the best way to disseminate the information to ensure the public is well informed about AIDS."

This, says Clayton, will be a big job. "We have [to work against] a plague mentality", he says. "We have a situation in which everyone's heard of AIDS, but a significant minority don't believe the experts are telling the truth. I get letters and calls from people who accuse us of lying, of hiding the truth about mosquitoes and food handlers and the dangers they pose."

It is no use trying to convince this minority, says Clayton, "so we have to try and reach the rest. I believe there is a significant majority who do understand the transmission factors".

Included in this majority, of course, are doctors. However, Clayton says some doctors and hospitals are still too secure in the belief they won't come in contact with the AIDS virus. "Some are resisting our health care setting guidelines. They just came out [in November] but

they've been known for a long time. The precautions are universal, and have been promoted for years as a means of preventing the spread of hepatitis B: Wear gloves anytime you anticipate coming in contact with body fluids. For doctors, this means they have to change their gloves after every patient. It could get very expensive, especially for [some small] hospitals, so they resist. They say, 'Our hospital has never had an AIDS patient and we're pretty sure [it] won't'. They are right, their chances are small. But when you're standing before the judge..."

Clayton says he gets calls from doctors in private practice wondering if they should test all their patients. "We say, 'No! Practise infection control using the established guidelines'. Everyone [understands] clearly if they think about it: AIDS is primarily a sexually transmitted disease, and very easy not to get."

Doctors are invited to call the FCA with questions, opinions or suggestions: (613) 957-1774. FCA laboratories provide the reference test for HIV infection, and can help answer scientific queries. Specific guidelines are available for some specialties and the centre can provide the latest statistics on virtually any AIDS-related matter. FCA experts address health care workers and AIDS support groups regularly. They can also provide doctors with information on community-based AIDS services throughout Canada. Funds are available for some activities.

With their many responsibilities, FCA staff are overworked. "We could maybe get by with 30 people, but a year and half ago I said we could get by with seven", says Smith.

Though silent about how much, he says the FCA has requested more money from Ottawa. However, he readily admits that the AIDS crisis can't be solved by dollars alone.

"Maintaining flexibility in the response that you make is just as important, because the issue changes and adds dimensions all the time." ■